

Yale CANCER
CENTER

answers

WNPR Connecticut Public Radio



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Pediatric Cancer Survivorship:
The HEROS Clinic

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Yale Cancer Center Answers

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Welcome to Yale Cancer Center Answers with Dr. Ed Chu and Dr. Ken Miller, I am Bruce Barber. Dr. Chu is Deputy Director and Chief of Medical Oncology at Yale Cancer Center and an internationally recognized expert on colorectal cancer. Dr. Miller is the Director of the Connecticut Challenge Survivorship Program and is also the author of "Choices in Breast Cancer Treatment." If you would like to join the discussion, you can contact the doctors directly at canceranswers@yale.edu or 1888-234-4YCC. This evening Ed Chu is joined by Dr. Nina Kadan-Lottick, a Pediatric Oncologist and the Director of The HEROS Clinic for Pediatric Cancer Survivors at Yale Cancer Center.

- Chu Let's start of by defining cancer survivorship, cancer survivors.
- Kadan-Lottick The National Cancer Institute would define cancer survivors as any individual who's experienced a cancer diagnosis and is trying to maximize their quality of life and their health.
- Chu Is there any difference in definition between say, a pediatric patient as opposed to an adult patient who survives cancer or who is diagnosed with cancer?
- Kadan-Lottick Yes, there are some important differences because of the developmental and physical milestones that should occur during childhood that can be disrupted by the cancer. These things can include progressing through puberty, they can include fertility because there can be different vulnerability of young boys who are exposed to therapy, and this can also include effects on the brain and learning because the brain is still forming during those periods of time.
- Chu Let's get into that in a little bit more detail later. In general, how many cancer survivors are there here in the United States would you say?
- Kadan-Lottick There was an estimate of childhood cancer survivors, so this would include people who are of any age now but had a diagnosis of cancer under the age of 21, and it is estimated that approximately one in five hundred young adults between the ages of 20 and 39 in the U.S. is a childhood cancer survivor; that corresponds to several hundred thousand people. Because childhood cancer survival rates continue to increase the numbers, we are going to have more and more people. Currently 80% of children are long-term survivors of their cancer.
- Chu That is also one of the distinguishing features between pediatric cancers and adult cancers. In adulthood there is still a relatively small number of cancers that we can say we can cure, but for the diseases that you take care of in the pediatric population, that is significantly different.

3:05 into mp3 file http://www.yalecancercenter.org/podcast/Answers_Feb-01-09.mp3

- Kadan-Lottick It is. For some of our leukemias and kidney tumors, and others, we have actually reached survival rates well into the 90s and are now talking about decreasing therapy so that we can minimize adverse outcomes later in life.
- Chu And these are cancers even in the most advanced stages?
- Kadan-Lottick Absolutely. How well we have conquered it depends on what the cancer is, but we have done particularly well for leukemias and kidney cancers.
- Chu Just curious Nina, if you compare the rates of pediatric patients surviving their bout with cancer now, as opposed to say 10 or 15 years ago, how are we doing?
- Kadan-Lottick It is dramatically different. In the early 1970s most of these cancers were uniformly fatal, so we have gone a very long way in a short amount of time. We have done it by having academic centers like Yale that participate in clinical trials that team up clinicians with researchers so we are always offering the best available therapy and the newest ideas that are coming down the pike so that our patients can benefit from them. That is how we have marched forward, instead of being content with the status quo of those low cure rates we have researched new ideas that were promising and that paid off.
- Chu It has also been pretty impressive to me, as an adult oncologist watching the pediatric world, how the major pediatric centers have really come together to form a network, if you will, to develop innovative state-of-the-art clinical trials for each of the different cancers afflicting pediatric patients.
- Kadan-Lottick There is a network of 270 centers in the United States that all participate in the same clinical trials so that we can meet our enrolling goals and go through a novel, exciting idea every year or two and move on to the next idea. In that way we have been able to progress, but this really speaks loudly that children should be treated at an academic center to get the best available treatment, and I guess that would be true for adults too, but adults do not have that same kind of treatment pattern right now, where they are treated only in academic centers or in partnership. That is something we have also realized with survivorship, while children are initially treated in the academic center, we expect and want the children, or young adults, or even middle-aged adults, to get their care in the community with a high-quality primary care doctor because the issues that we think about later in life are ones best suited to be managed by someone who has a long term relationship with the patient and is focused more on wellness care rather than our environment which is often focused on critical care.

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- Chu What are some of the short term and long term consequences of cancer therapy, especially for pediatric patients? Let's start off with the short term, but obviously in terms of cancer survivorship the key issues are the long term consequences.
- Kadan-Lottick Short term we see problems in growth and in development, and problems in terms of becoming part of the peer group and integrating back into the peer group; those are some of the immediate problems. We also see immediate problems with family functioning because when a child has cancer it is so devastating for the family financially and emotionally that there is a higher rate of divorce, and the economic status of the family usually decreases considerably because someone may have to stop work to care for the child. Long term, we have appreciated that therapy, even though we are winning the battle against cancer, about two-thirds of children who are survivors of childhood cancer will experience at least one significant chronic health condition due to the treatment, not the cancer. One-third will develop a severe problem related to the previous treatment and it can affect almost any organ system depending on the therapy, everything from problems with heart function and heart failure, infertility, hormone problems, problems with learning and thinking, problems with lung scarring and kidney function. Also, there is about a six fold increased risk of a new cancer, a different cancer, which is higher in certain groups that get radiation.
- Chu This risk of a secondary cancer, does that risk ever return to normal or is there always a continued risk throughout their entire life?
- Kadan-Lottick It depends on the target tissue, for breast cancer the risk increases with time. The risk starts increasing about 10 years after radiation exposure to the chest and continues to increase. Another example would be certain chemotherapy agents that increase the risk of leukemia, but that risk peaks at 10 years. It varies on the exposure and it varies on the target tissue of the chemotherapy or radiation and that is why we have a center like our HEROS Clinic, which we view as a consult clinic where we can give an individualized monitoring plan that can then be carried out by the primary care doctor. We can give guidance in an area where we have the expertise, and it is really not reasonable to expect a primary care doctor, or a general oncologist, to have this expertise. We can list exactly what the patients had for them by reviewing the records and then give very individualized recommendations on what their wellness care and what their ongoing screening should be.
- Chu Are there any strategies to try to prevent or reduce the risk of some of these long-term side effects from happening?
- Kadan-Lottick There are. One of the important ones is that many of our clinical trials are reducing up-front therapy, because we have realized that we can achieve cure without giving as aggressive

10:38 into mp3 file [http://www.yalecancercenter.org/podcast/Answers Feb-01-09.mp3](http://www.yalecancercenter.org/podcast/Answers_Feb-01-09.mp3)

therapy, and we are examining that very carefully. We also are starting to give protectants at the time we give certain toxic therapy to protect the heart, protect the kidneys, and protect hearing. A third strategy is that once the problem develops, we are now developing interventions to improve it, so there are ongoing studies in using stimulants for learning problems after chemotherapy. There is an interest in health style modification such as exercise and nutrition to decrease the risk of second cancers, obesity, and the risk of heart problems, and those are being actively studied. We spearhead and participate in multiple studies such as these in our HEROS Clinic, so that is our other dual role. First and foremost we are a clinic, but it is very important for us to be a living laboratory and continue to learn more on how to improve wellness in survivors.

Chu Nina, you are the Director of the HEROS Clinic, does HERO stand for anything in particular?

Kadan-Lottick It does. We started off with HEROS because we wanted an acronym that was powerful and we often use the word “hero” when we refer to our survivors and their family members. So then we made it work backwards and it does fit nicely; Health Education Research Outcomes for Survivors. We were very fortunate to have our department of pediatrics at Yale Cancer Center, and the Tommy Fund, start off our clinic about 6 years ago, then we received substantial funding from the Connecticut Challenge so that we have been able to expand our services to include a neuropsychologist that screens every survivor for learning problems and emotional distress. We include a nurse educator who does focused education with individuals and composes a one-page treatment summary for every patient that they can have wherever they go; whether it be an emergency room or a new doctor, they can see quickly what their treatments were and what problems they are at risk for.

Chu So every pediatric patient who survives their cancer will come to the HEROS Clinic and will be seen and evaluated?

Kadan-Lottick Yes. We see all our patients that were treated at Yale, which includes most of Southern Connecticut and parts of New York, but we also have referrals from other centers, so you do not have to be originally treated at Yale. We have seen patients that have been treated all over the country who come to get an evaluation. Either they are seen once, or they are seen once every few years, but the idea is really to do this with teamwork, with their primary oncologist or primary care doctor who then does the actual care.

Chu How many new patients do you see each year in the HEROS Clinic?

Kadan-Lottick We see about 50 new patients a year, and we have about 270 patients now. One area I am

14:02 into mp3 file http://www.yalecancercenter.org/podcast/Answers_Feb-01-09.mp3

very interested in, in my research, is that there are 13,000 childhood cancer survivors of any age in Connecticut; obviously we are only seeing the tip of the iceberg. I think there are several reasons for this, the most important one being that I do not think the survivors self-identify themselves as having unique health needs. I think that they feel like since they are done with therapy, they are done, and they have no clue that they could be at risk for these problems, which are often silent. The second main reason is that it can be really hard to go back to a cancer center once your treatment is done. One of the areas that Yale, and our program also, is very interested in is how to do community outreach through virtual care, or directly teaming up with primary care doctors to be able to provide this critical information to patients without physically seeing them.

Chu You are listening to Yale Cancer Center Answers and we are here in the studio discussing pediatric cancer survivorship with our special guest Dr. Nina Kadan-Lottick.

MedicalMinute

Breast cancer is the second most common cancer in women. About 3000 women in Connecticut will be diagnosed with breast cancer this year, but earlier detection, noninvasive treatments, and new therapies are providing more options for breast cancer patients and more women are able to live with breast cancer than ever before. Beginning at age 40, every woman should schedule an annual mammogram, and you should start even sooner if you have a risk factor associated with breast cancer. Screening, early detection, and a healthy lifestyle are the most important factors in defeating breast cancer. Clinical trials are currently underway at federally designated comprehensive cancer center such as the Yale Cancer Center to make new treatments not yet approved by the Food and Drug Administration available to patients. This has been a medical minute and you will find more information at yalecancercenter.org. You are listening to the WNPR Health Forum from Connecticut Public Radio.

Chu Welcome back to Yale Cancer Center Answers, this is Dr. Ed Chu and I am here in the studio this evening with Dr. Nina Kadan-Lottick, a Pediatric Oncologist and specialist in the area of Pediatric Cancer Survivorship here at Yale Cancer Center. Before the break, we were talking about the HEROS Clinic. Maybe for those who may have missed that piece, could you review with us what the HEROS Clinic does here at Yale Cancer Center?

Kadan-Lottick The HEROS Clinic is a consult clinic for survivors of childhood cancer who are of any age now. What we do at the clinic is, before the patient comes we review all their medical records and summarize their treatment in one page, then we do a comprehensive visit in which we screen the patient for medical and social problems or adverse outcomes from their previous therapy. For many people they have nothing, but we give a recommendation for

17:02 into mp3 file [http://www.yalecancercenter.org/podcast/Answers Feb-01-09.mp3](http://www.yalecancercenter.org/podcast/Answers_Feb-01-09.mp3)

what ongoing follow-up should be so any problems that could develop could be caught early, and we also educate those survivors on how to change their own individual health habits to maximize their health and to prevent these problems from occurring.

Chu What specific services are available to patients and their families in the HEROS Clinic?

Kadan-Lottick Our HEROS team is a multi-disciplinary team that includes the pediatric endocrinologist, neuropsychologist, nurse educator, oncologist, and research coordinator. What patients are offered on a clinic visit is, they are seen by the physician and they are screened by the neuropsychologist for any learning problems or emotional distress that could be resulting from their previous therapy. They spend time with the nurse educator to learn about their past treatment and what things they should watch out for, and they are offered any research studies that may be available, that they may be eligible for and interested in, which is totally optional, but they can avail themselves of that if they wish. Then after their visit they are given a written summary that includes their treatment on one page as well as recommendations for ongoing care. Obviously if we identify any problems we also arrange appropriate follow-up and communicate directly with the primary care doctor to work in partnership because that is the whole model, we see ourselves as a consult clinic that works closely with oncologists and primary care doctors to care for these patients.

Chu And again, you are seeing patients that were not only treated here at Yale, but treated by other pediatric specialists throughout the state and around the local regional area.

Kadan-Lottick Exactly. We see individuals who were diagnosed with a cancer under the age of 21, so sometimes that has included patients who were treated by medical oncologists and pediatric oncologists at other centers who come to our center to have these different services. They have heard about our clinic and want care, or want to participate in one of our research studies.

Chu This really is a terrific program that you are offering to patients and their families. I am just curious, are there other centers, either in the State of Connecticut or around the country, that offer the same type of services?

Kadan-Lottick For pediatrics, I think that CCMC in Hartford is starting a program by Dr. Eileen Gillan. There was a mandate nationally by the Children's Oncology Group and the NCI that every center that treats pediatric cancer patients should have a survivorship program. Now what it means is defined a little more broadly. In some places that may mean that your regular oncologist would see you and discuss some of these things with you. Our program is really unique because it's multi-disciplinary and involves specialists from the areas in which people

20:39 into mp3 file http://www.yalecancercenter.org/podcast/Answers_Feb-01-09.mp3

can have potential problems; we have psychosocial support and we have research studies that can help patients who are experiencing problems.

Chu It would seem also that you and your team are focused in this particular area, and I know that in the adult world we have a similar type of cancer survivorship clinic. Truthfully, as much as we like to think we know the issues, that team is much better prepared to handle experiences and deal with all of the various survivorship issues.

Kadan-Lottick Absolutely. It is an emerging subspecialty of oncology because we now have the luxury of so many survivors. This is not an area of expertise that we had during oncology training because there were not enough survivors to focus on and this is something that I spent extra time and extra training doing both in clinical work and research work to develop this expertise. The real key with this though is that many times the key information has to do with being aware of what to screen for and what recommendations to give, and the actual care that is delivered can be delivered by a primary care doctor. It is a very natural partnership and it is very well suited to be a subspecialty clinic with occasional visits.

Chu Nina, before we forget, could you list the number if anyone out there listening wants to get more information about the services that are available to them at the HEROS Clinic. Maybe give them the number and if there is a website.

Kadan-Lottick We have a website, if you Google Yale HEROS Clinic you will find it. Our phone number is 203-785-4640, and that is the number for our pediatric hematology/oncology section at Yale, and Teneta is our stellar HEROS' nurse, and she would be happy to talk to you more about details in the clinic. Also, she does a lot of hand holding and walking patient's through the process so that we can get your records and so that you will know what to expect on the clinic day. The number is 203-785-4640 and you can either make an appointment or you can ask to speak to Teneta, Christy, or me to learn more about the clinic.

Chu Great, thanks. At the end of the show I'm sure we will repeat those numbers as well. In general, how often do you recommend a patient be followed up in your clinic?

Kadan-Lottick I would say at least once, and then, depending on the type of treatment a patient has had and what the risk is for subsequent problems, we decide to see them yearly, every couple of years, or every few years. For example, some of our highest risk groups are individuals who had brain tumors, who had radiation exposures, or who were treated with strong chemotherapy at a very early age, such as under the age of 3. Those would be our highest risk groups for monitoring for problems. Still, they may not have any problems, but these are the groups that we would like to see more often to make sure we catch anything early.

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- Chu These would be neuropsychological development type issues?
- Kadan-Lottick Neuropsychological development problems and growth problems with hormones. For example, with growth hormone deficiency after radiation to the head and neck area, this is a problem that can be very easily missed because many patients do not grow well during therapy. Then what happens is, after therapy ends they pick up their growth and clinicians are very content that they've done fine, but what can happen is that they are going through puberty and they are growing rapidly, but that is all the growth they are going to achieve, so it is really a false reassurance. It is not because people are not taking care of them carefully, it is just because this is a very specialized type of patient population with some very unique things to monitor for by people who see this often. That is an example where you really have to catch something quickly. Neuropsychological problems are another that is very important because they do not appear for a couple of years after the treatment exposure; they occur with problems of working memory, attention, ability to organize thoughts, and processing speed. But for children in school, the school no longer associates these problems with the therapy that occurred years ago and these children can get in trouble because these problems can manifest as apathy or behavioral problems, or be perceived that way when they are not. Then the children can fall farther and farther behind and we know that children that get early intervention do much better than those who do not, and those who get special education services, and often these problems do not affect intelligence, but how this type of information is processed. Knowledge is truly power in this situation, especially before children lose their self-confidence or feel that they are too far behind to catch up.
- Chu It is interesting, in the adult world we call this chemo-brain, and many patients will describe a kind of fogginess and things just aren't clear. For a long time we did not really appreciate what this was due to, but I think now we have a much better understanding and it clearly has to do with the chemotherapy effects.
- Kadan-Lottick It is. Even in individuals who do not have brain tumors and who do not have radiation to the head, chemotherapy can cause these problems, and especially in our society where there is so much informatics and expectation of rapid response and multitasking, this can really limit an individual or make them feel that something is terribly wrong. A lot of times what is really important is that we identify the problem and we encourage individuals to do things differently in a way that they can maximize their success and compensate for some of these issues. The other thing that is also helpful is that this may not be a person who would feel very successful being in a place where there is a lot of chaos and rapid turnaround and multiple deadlines that are overlapping; this person may do better with project-oriented work or a career where you can be more thoughtful.

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- Chu It is amazing how time flies. Before we sign off could you again give the number for anyone who would like to get more information relating to the HEROS Clinic.
- Kadan-Lottick The number is 203-785-4640. You could make an appointment, or ask for Teneta, or for me, Dr. Kadan-Lottick.
- Chu You can also probably go to the Yale Cancer Center website, yalecancercenter.org, for more information as well.
- Kadan-Lottick Absolutely. We have a link through Yale Cancer Center as well.
- Chu Nina, it has been great having you and we look forward to having you come back for a future show to talk more about the research that you are doing with the HEROS Clinic. You have been listening to Yale Cancer Center Answers. I would like to thank my guest, Nina Kadan-Lottick, for joining me this evening. Until next time, I am Ed Chu from Yale Cancer Center wishing you a safe and healthy week.

If you have questions or would like to share your comments, go to yalecancercenter.org where you can also subscribe to our podcast and find written transcripts of past programs. I am Bruce Barber and you are listening to the WNPR Health Forum from Connecticut Public Radio.